

**BREAKING THE BARRIERS OF ORGAN DONATION
IN THE AFRICAN AMERICAN
COMMUNITY**

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DEDICATION

This dissertation is dedicated to the memory of Sandra Elaine Garrett Whitehurst.

ABSTRACT

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The focus of this final project dissertation is to address the barriers of organ donation in the African American community. The context for this project is Sentara Norfolk General Hospital in Norfolk, Virginia. This is a case study focusing on those barriers in an attempt to increase organ donation rates in the African American community. It was discovered that educating community clergy about organ donation will change the mindset of the African American community in terms of organ donation. It was also discovered that the hospital chaplain with specialized clinical training, early interaction with the family and making the preliminary mention of organ donation makes a significant difference.

INTRODUCTION

There are more than 98,000 people on the waiting list for an organ transplant; of that number over 26,000 are African Americans according to the United Network for Organ Sharing.¹ The United Network for Organ Sharing manages the transplant waiting list for the United States. The total number of people waiting for kidneys in particular is over 70,000, and over 24,000 of those (thirty-four percent) are African Americans. This information makes it clear that organ donation should be a priority in the African American community. However, there is a barrier in the African American community, and it is found within the African American Church. The African American Church has been the vehicle of change in the African American Community. Therefore, the important issue of organ donation in the African American community should start in the church. In order for this to happen, it is essential that clergy be educated about this important topic.

It is imperative that something be done immediately to encourage people to help those on the organ donation waiting list. The Department of Health and Human Services decided to tackle this problem by calling for a collaboration of major hospitals in

¹ "Waiting List Candidates." United Network for Organ Sharing, 2006. <http://.html// #electronic> (9/23/06).

America to examine the practices surrounding organ donation and make suggestions for improvement. This project, however, focuses only on the African American Community with the hopes that it will impact the organ donation waiting list. The experience of losing a family member (Sandra) has led the writer to take a hard look at the reasons why organ donation appears to be a subject not discussed in the African American community. Sandra's life might have been spared if more African Americans were listed on the bone marrow donor list. Bone marrow transplants do not take place in the community or surrounding area in which this researcher lives. The percentage of African Americans on the organ donor registry is also low. The organ donor registry is a list of people who wish to be an organ donor if they are ever declared brain-dead. Organ transplants do take place in the writer's community and in particular in the place where she ministers, Sentara Norfolk General Hospital. The writer is a clinical chaplain at Sentara Norfolk General Hospital. Sandra's death has led her to be an active advocate for organ donation. It is clear to her that not enough is being done in the African American Community to educate the community about organ donation. Her current position has opened many doors to educate the community about the organ donation process.

There are preconceived notions in the African American community surrounding organ donation, and it is important to study the myths and barriers concerning this topic. In her position as a hospital chaplain she has talked both with families who did donate their loved one's organs and also with those who did not. The research methodology is case study, where each part can be analyzed. Families were interviewed in a conversational style due to the writer's sensitivity to their grief. Through the research and

case study, the hope is to enlighten the African American community so that lives will be saved and the quality of life will be enhanced.

This researcher discovered that historically, African Americans mistrust the medical system, which is one of the larger barriers to organ donation. The cultural beliefs surrounding death were also explored. Identification of theological beliefs that influence families who are struggling with the decision of organ donation was essential. Not only does the writer hope to enlighten the African American community, but also the writer hopes to make African American clergy aware of this serious problem. Through their education, hopefully the theological beliefs of their congregants can be explored.

Discussions about organ donation in the twenty-first century are relatively new in both the health care community and the African American church. The health care industry and technological advances have done a good job of prolonging life expectancy; because of that, there are more people than ever on the organ donation waiting list.

The reader will find in chapter one a detailed account of the writer's role as chaplain in the organ donation process. The literature on this topic is limited. Past history shows that it was not a priority; the literature found, however, supports the theory that there is a definite correlation between organ donation and one's faith tradition. This description can be found in chapter two.

Biblical themes will be explored in chapter three. The writer's experience as the chaplain supporting families through the organ donation process gave her an opportunity to see, in biblical terms, what they were struggling with. Most families supported during these stressful times centered on organ donation have been African Americans, and all of them were Christian. Their primary theological concern was keeping the body intact for

the resurrection. Grounding the project in Paul's first letter to the Corinthians enables the reader to understand that the body is sown a natural body and it is raised a spiritual body. If there is a physical body, there is also a spiritual body. (1 Cor 15:42 –53)² The act of neighborly love is also an overwhelming theme In everything do unto others as you would have them do to you; for this is the law and the prophets. (Matt 7:12)

The writer is impressed with the modern liberation theologian David Tracy, because he describes Christian theology as a discipline that attempts to correlate the meaning and truth of the Christian faith (its scriptures, doctrines, rituals, witnesses, symbols, etc.) with the meaning and truth of the contemporary experience. Organ donation is a contemporary experience, but we can find Christian virtues throughout the Bible supporting the act of donation of organs. Chapter three will also address the historical and theological foundations of this topic.

Chapter four will elaborate on the case study method and how it was utilized in this project. The most effective way found to explore this topic was by case study. The case study method was chosen not only because it allows for sensitivity, but also because of the many facets involved in the decision making process for families. The interviews revealed that a few of the assumptions made by families were false. The three African American family members of organ donors were all people of Christian faith, but varied in denominational ties and church attendance. There will be more details about that in chapters four and five.

² Unless otherwise indicated all Bible references in this paper are to the New Revised Standard Version Bible (NRSV) (Grand Rapids, MI: Word Publishing. 1989).

CHAPTER ONE

MINISTRY FOCUS

One of the saddest times of this writer's life was the death of her cousin Sandra. The writer was an only child until the age of eleven, so her cousins were like sisters and brothers to her. Many Sunday afternoons and holidays were spent together at their grandparent's home. They supported one another through childhood, teenage years, and adulthood. They continued the tradition of family gatherings with their own children long after their grandparents were gone. When Sandra was diagnosed with Leukemia it was extremely hard for the entire family. Everyone, however, was optimistic that she would be cured. The doctor recommended a bone marrow transplant. It was explained that this was the best hope for a complete cure. Sandra's parents and siblings were tested to see if they would be compatible donors, but none of the family matched Sandra's bone marrow 100 percent. The family did not give up and was encouraged by the fact that she could receive a transplant from someone on the bone marrow donor list. This is a list of people who have generously agreed to be a donor for someone that they do not know. Sandra underwent chemotherapy to kill white blood cells. She lost her hair and became weak, but was hopeful that this procedure would be successful. Sandra was in isolation because the

chemotherapy compromised her immune system. When it was time for the transplant to take place, it was discovered that there was no donor who exactly matched Sandra. However, there was a donor that closely matched her, and that donor was tried.

Sandra underwent the bone marrow transplant procedure, and the family was hopeful that it would be successful. Their hopes were dashed however, when in a few days, Sandra's body rejected the stranger's bone marrow. Sandra was placed on life support and after a few days the decision was made not to prolong her suffering but remove her from life support. Her family stood around her bed singing hymns, praying and telling stories as Sandra made her transition from this earthly life to her eternal life of peace. It was a time of reflection upon the many good and meaningful times that they shared as a family.

Looking back on that time, it was clear to the writer that she had been used by God to help her family get through what described as the worst time for their family. This writer realized that God was not only exposing her gifts for the ministry, but also for her family and the many families that she would eventually impact. She watched and listened as the hospital chaplain visited several times a day, and was in awe. She left the hospital and that experience knowing that she wanted to provide a pastoral presence and spiritual support to families struggling with the loss of a loved one. That cool day in April started her thinking about God's call on her life. She began to see that she had been avoiding ministry for about a year. Sandra's illness and death made her surrender to the call. She was drawn to hospital ministry and felt a sense of peace whenever she thought about it. She began to seek information about the process of becoming a hospital chaplain and the qualifications. One of the first things she did was to seek guidance from her spiritual

mother about the requirements of her denomination, the African Methodist Episcopal Church. It was ironic that the late Rev. Arthur Mae Lawson also had a passion for chaplaincy, even though she was pastoring a small congregation. The writer is a fourth generation member of the AME (African Methodist Episcopal Church) and served the church in many capacities as a Layperson. She never imagined that she would one day be an ordained minister. She also never imagined that Sandra's death would impact her ministry with families facing a decision about organ donation.

In her quest to become a hospital chaplain, she found that she would need to prepare herself academically and clinically. The writer's academic aspirations were put on hold to allow time to raise two children (which left her limited time to attend college on a full-time basis). As the writer's children became more independent, more time was devoted to completing the undergraduate degree in business administration. She knew that in order to be a Board Certified Chaplain, she would need not only to have an undergraduate degree, but also to complete four units of Clinical Pastoral Education (CPE) and a Masters of Divinity. She enrolled in CPE and felt at home ministering to the sick and those in crisis. She found healing in the CPE process, which was a freeing experience for her. The wounds of abuse, grief, disappointment, and feelings of failure laid open while God, her caring supervisor and her peer group helped her in her healing. The CPE experience helped her to refine the gifts that God has given her. There wasn't any doubt in her mind that chaplaincy was what God had called her to do. Her CPE supervisor encouraged her to continue to prepare herself for chaplaincy.

She completed a one year's residency in chaplaincy and was offered a part time job at Sentara Norfolk General Hospital. Sentara is a level one trauma center, and she

was assigned to the Burn/Trauma Intensive Care unit, Neuro-Intensive Care unit, Oncology unit, and the Emergency Room. Her position has grown into a full-time position with the added responsibility of being the FCC (Family Communications Coordinator, further referred to as FCC). This position was funded by a grant from the Division of Transplantation of the Department of Health and Human Services. The grant was to study if there was any correlation between consistent family support by a chaplain and the consent rate from the families of potential organ donors. She became passionate about the organ donation process. Reflecting upon it now, she realizes that Sandra's death is behind her passion. Organ donation is a way of finding meaning in Sandra's death. Sentara is an organ transplant center, but they do not perform bone marrow transplants. She realizes that she can still make a difference, however, in the organ donation process. The organ donation donor and the bone marrow donor are similar in that they both must have an open mind. The bone marrow donor must be alive, and make the decision to become a donor. The organ donor can also be alive, and can donate a kidney to the person in need. This is often a family member, but sometimes is a stranger or a person outside of their family. The organ donors that will be referred to in this project, however, will be those that are deceased, and whose families will be making the decision to donate. In Sandra's case, if a perfect bone marrow match could have been found, Sandra's chances of survival would have been much greater. If more donors of African American descent had been on the list, maybe Sandra would have survived. The reality is that the percentage of people donating organs and bone marrow is very low, and is even lower for African Americans. Those suffering from Leukemia and other blood-related diseases find that this is a major concern. According to the 2004 Biennial Report of the National Bone

Marrow Donor Registry, at any one time, there are 1.3 million people waiting for a match for bone marrow, there are 3000 people searching for a donor, and there are 5.5 million volunteer donors waiting to give.³ It is important to note here that those waiting to give might not ever match one that is waiting to receive. There are a lot of factors that determine a match, but being of the same race is the most important. Sandra was one of the unfortunate ones who did not match anyone on the list 100 percent. Her donor, however, was an 85 percent match, and her body still rejected the marrow.

Sentara Norfolk General Hospital

Sentara Norfolk General Hospital, where this writer is privileged to work, is a level one trauma center in the Southeastern part of the state of Virginia. It is a five hundred sixty-nine bed facility and provides medical coverage for the Hampton Roads area. The Hampton Roads area is comprised of the cities of Norfolk, Virginia Beach, Chesapeake, Newport News and Hampton. Sentara's area of coverage is expanded to the Eastern Shore of Virginia, Eastern North Carolina and many rural outlying areas through the air ambulance service which is called Nightingale.

Norfolk General opened in 1888 as a twenty-five bed retreat center for the sick, and was at that time located in downtown Norfolk. The hospital moved in 1896 to a new building that housed beds at a cost to patients of \$2.75 per day, which included meals. Norfolk General continued to grow and, in 1986, a new wing was added with three hundred seventy-five additional beds. They have continues to add through the years: eleven intensive care units, along with an acute care facility, women's health, a sleep disorder center and an extensive rehabilitation center. In 1987 the name Sentara was

³ U.S. Department of Health and Human Services, Division of Transplantation, *Biennial Report of the National Bone Marrow Registry*, 2004, P.54.

adopted, and, during the 1990s, several hospitals were acquired along with many nursing homes and urgent care facilities. In 1989, Sentara Norfolk General Hospital performed their first heart transplant. Since that time they have performed kidney, liver, and heart transplants. Sentara Norfolk General is also the chief teaching hospital for the Eastern Virginia Medical School. Sentara does not have a pediatric department, but is in partnership with the Children's Hospital of the King's Daughters next door, which provides trauma care for their incoming patients. Norfolk General gained national attention when the first in-vitro baby, Elizabeth Carr, was delivered at the hospital. Sentara has been named among the top ten integrated health networks in the United States. Sentara has also been named for several years as one of America's best hospitals in cardiology and rheumatology by U.S. News and World Report.

The Hampton Roads area which Norfolk General serves comprises a diverse population of 1.6 million. Sixty-two percent (62%) of the population is Caucasian, thirty-one percent (31%) is African American, and four percent (4%) is of non-specific origin. The educational level of persons 25 and over is twenty-seven percent (27%) high school graduates, twenty-six percent (26%) with some college, fifteen percent (15%) with an undergraduate degree, and eight percent (8%) with a graduate degree. The annual median income for families is \$49,000 and eight percent (8%) of the population lives below the poverty level.⁴

Norfolk General is the only level one trauma center and transplant center in the Hampton Roads area. Providing ministry in this hospital gives this writer an opportunity to journey with trauma patients, families and the staff. There are times when patients will

⁴ "City of Norfolk," Demographics, 2006. (11/9/06). <http://www.Norfolk.gov/about/demographics.asp>

come in with a devastating neurological injury. These patients are often identified as potential organ donors depending on the severity of the brain injury. Those patients are identified with a Glasgow Coma Scale (GCS) of four or less. The scale was published in 1974 by Graham Teasdale and Bryan J. Jennett, professors of neurology at the University of Glasgow, and is reproduced below.

Table 1 GLASGOW COMA SCALE⁵

Eyes open	Spontaneously (eyes open does not imply awareness)	4
	To speech (any speech, not necessarily a command)	3
	To pain (should not use supraorbital pressure)	2
	Never	1
Best Verbal Response	Oriented (to time, person, place)	5
	Confused speech (disoriented)	4
	Inappropriate (swearing, yelling)	3
	Incomprehensible sounds (moaning, groaning)	2
	None	1
Best Motor Response	Obeys commands	6
	Localizes pain (deliberate or purposeful movement)	5
	Withdrawal (moves away from stimulus)	4
	Abnormal flexion (decortication)	3
	Extension (decerebration)	2
	None (flaccidity)	1
Total Score _____		

A neurologist or neurosurgeon as to what interventions accesses the patient, if any can be done. Many times surgery is performed, because everything is done to save the patient's life. Unfortunately there are times when surgery will not change the outcome. These patients are often there as the result of traumatic force to the head such as gunshot wounds, falls, or motor vehicle accidents. The injuries can also be sustained from a

⁵ J. Claude Bennett and Lee Goldman, "Head Injury," in *Textbook of Medicine*, eds., Gabrielle F. Morris and Lawrence F. Marshall (Philadelphia: W. B. Saunders Company, 2000), 2179.

stroke, aneurysm, or hypoxic injury. Regardless of the cause, it is a devastating injury that will change a family forever.

This writer ministers to these families and supports them through the grieving process. She helps them to draw on their strength and to find meaning in their situation through their faith tradition. Most of the families are Christian, but there are times that pastoral support has been given to those of other faiths. The writer has the opportunity to journey with a diverse group of people with diverse faith backgrounds. Patients range from fifteen years old to seventy-five years old, male and female, all ethnic cultures and economic backgrounds. As a pastoral caregiver, the main concern is to support and be compassionate, because for many families this is the most vulnerable times of their lives. In her role as chaplain and, in the situations of potential organ donation, as Family Communications Coordinator (FCC), she is there to facilitate conversations between the medical staff and the family. She listens for an understanding of the grave prognosis and the concept of brain death. The standard of brain death was established by the President's Commission report of 1981 as "irreversible cessation of all brain function including those of the brain stem".⁶ States differ on how brain death is determined, but the Commonwealth of Virginia requires two physicians, of which one must be a Neuro-Specialist, to diagnose brain death. This is a lot of information for families to absorb during such a tragic time; therefore the FCC listens for an understanding. If there seems to be a lack of understanding, the FCC will get someone from the medical staff to explain it again and in layman's terms.

The medical staff working in the field of neuroscience at Norfolk General Hospital is predominately Caucasian. There is one African American nurse in the

⁶ Ibid., 2027

Burn/Trauma Unit and two African American nurses in the Neuro-Intensive Care Unit.

There are fourteen neurosurgeons, and only one is of African American descent (neurosurgeons are in private practice and are consulted for neurology for neurosurgery patients). There are no African Americans in administration at Norfolk General Hospital, but there are several African American managers.

Norfolk General Hospital is proactive concerning organ donation. Norfolk General Hospital, along with two hundred hospitals across the country, joined together at the direction of the Health and Human Services Secretary Tommy Thompson to increase organ donation rates. This is called the Organ Donation Breakthrough Collaborative. The collaborative is intended to dramatically increase access to transplantable organs. Norfolk General joined with the Organ Procurement Agency, LifeNet, to increase their organ donation rate; the goal is a seventy-five percent (75%) consent rate. It is this researcher's goal to increase organ donation rates particularly in the African American community, as well. It is important to note here that Life Net's rates among African Americans are below the national average. LifeNet has one African American transplant coordinator, and this coordinator is often the one who approaches families.

CHAPTER TWO

THE STATE OF THE ART IN THIS MINISTRY PROJECT

The first organ transplant took place in Boston in 1954, when a man donated a kidney to his brother. The donor was alive and this procedure led the way for many living donors. The first heart transplant took place in 1968, and this procedure is happening more frequently everyday. Much has been written about organ donation and organ transplant, but there is not a lot of literature written about African Americans and organ donation. This researcher found that to research the topic, *Breaking the Barriers of Organ Donation in the African American Community*, it was necessary to look at the barriers to health care in general for African Americans.

Mark Moran, in his article *Acting Out Faith Through Organ Donation*, suggests that the option of organ donation gives Christians a concrete opportunity to act as “people of the resurrection” by passing on the gift of life. He suggests that a pastoral mode of education is greatly needed in the local church, where people can think through, pray through, and make preparations well in advance of their own deaths concerning organ donation. Asking a grieving family to donate a loved one’s organs -- with its intimations of “body snatching” -- is not a simple matter. “The task requires a pastoral alliance that is

based on trust, faith and risking,” according to Moran. “One must be person-centered, empathic and able to respond to the feelings of the client or family.”⁷ Hospitals are turning to ministers, rabbis, and social workers to request organ donation from grieving families. The previous model used by the Organ Procurement Organization discouraged healthcare professionals from talking with families. Their thinking was that the requestor might be asked questions by families that they would not know how to answer. The problem that they found, however, was that the family was saying no more than saying yes. The Organ Procurement Organizations recognized that families were suddenly being approached by a stranger, who did not have the skill to work with grieving families. The Organ Procurement Organizations are also placing transplant coordinators in level one trauma centers to make sure that potential organ donor referrals are made in a timely manner. They have an office within the hospital and interact with staff daily to build rapport and provide education. This action was taken as a result of a study provided by LifeGift Organ Donation Center in Houston, Texas, showing that an In-house Coordinator made a difference in donation rates because of the early referrals.⁸ Organ Procurement Organizations are also hiring Family Support Counselors, who are usually psycho-socially trained, to approach families. The model that is being used now at Sentara Norfolk General Hospital allows for those who are trained in pastoral care, which

⁷ Mark Moran, “Acting Out Faith Through Organ Donation,” *Christian Century*, June 18, 1986, 57-59

⁸ Teresa J. Shafer, Ronald N. Ehrie, Kimberly D. Davis, Roger E. Durand, Samuel M. Holtzman, Charles T. VanBuren, Nicholas J. Crafts, and Phillip J. Decker. “Increasing Organ Recovery from Level 1 Trauma Centers: The In-House Coordinator Intervention.” *Progress in Transplantation* 14 (2004): 240-263.

encompasses family dynamics, active listening and grief counseling, to mention organ donation to families of potential organ donors. This is called the FCC protocol.

Race and Mistrust

Jennie R. Perryman, in the article *Moving beyond Attitudinal Barriers: Understanding African Americans' Support of Organ and Tissue Donation*, states that many African Americans do not sign donor registry cards because of the mistrust of the medical system. The fear is that, in signing the card, there will be a decrease in the quality of medical care received and even possibly the premature declaration of death.⁹

Rosalyn Watts, a nurse educator, states that the historical experience of African Americans is shaped by the institution of slavery, segregation, and racism in contemporary American society. Disparities in health care provide compelling evidence that issues of race for the descendants of slaves and other ethnic minorities persist in the twenty-first century. She states that it is imperative that all health care workers be sensitive to this issue.¹⁰

Clive Callendar, director of the transplant center for Howard University in Washington, D.C. and also the founder of the National Minority Organ Tissue Transplant Education Program (MOTTEP), explored why African Americans donate less frequently than Caucasians. He discovered five reasons: lack of information, religious beliefs, fear of premature death, mistrust of the medical community (that they would not be saved if they were in a terrible accident), and racist fears that their organs would only go to

⁹ Kimberly R. Jacob, Jennie R. Perryman and Michelle Doldren, "Moving beyond Attitudinal Barriers: Understand African Americans' Support for Organ and Tissue Donation," *Journal of the National Medical Association* 97, no. 23 (2005): 339.

¹⁰ Rosalyn J. Watts, "Race Consciousness and the Health of African Americans," *Journal of Nursing* 8, no. 1 (2003): 4

Caucasians.¹¹ There are definite negative attitudes toward organ donation, which are shared among many African Americans.

Hoping to stem the continuing expansion of the donation gap, the United States Department of Health and Human Services (DHHS) launched the Gift of Life Donation Initiative. This initiative is intended to make improvements in the supply of donated organs, as well as the protection of living donors, a top public health priority. Under the DHHS initiative, best practices have been identified for hospitals and Organ Procurement Organizations to create organizational cultures that promote organ donation. The Joint Commission on Accreditation of Healthcare Organizations identified issues for hospitals to aggressively address to increase organ donation, particularly in the minority community. In a White Paper that emanated from their Public Policy Initiative, many suggestions were made, including the following:

1. Employ grassroots efforts to raise awareness, change behavior and increase the rate of donation among ethnic and minority groups, and to reevaluate the priorities for organ allocation to identify opportunities to equalize access to transplantation.
2. Further studies should be conducted to enhance knowledge about the underlying causes of transplantation disparities and to create a basis for problem-solving.
3. Undertake initiatives to diversify the health care workforce, to reduce racial and ethnic disparities in access to transplantation.

This paper is a call to action to seriously tackle the problem of low statistics of organ donors in the African American community.¹²

¹¹ "Founder's Corner – Dr. Clive O. Callendar," Minority Organ Tissue Transplant Education Program, 2006, > (23 September 2006)

¹² Joint Commission on Accreditation for Quality in Healthcare, *Healthcare at the Crossroads: Strategies for Narrowing the Organ Donation Gap and Protecting Patients*. (2005). 37-38

Susan E. Morgan, in the article *The Power of talk: African Americans' communication with family members about organ donation and its impact on the willingness to donate organs*, discusses the issue of end-of-life discussions with family members. African Americans, according to Morgan, are more likely to donate their loved one's organs if they have had a conversation with their loved one about their wishes. African Americans appear to shy away from topics about death, leaving family members to make decisions regarding withdrawal of life support or life decisions. Families have not had a discussion about organ donation, therefore this leads to families saying no when approached.¹³

There is another side to organ donation that Jennifer Girod raises in her essay *Wading Through Blood and Suffering*. She makes the point that organ donation does not always save lives; some organ transplant recipients suffer tremendously, and some die more quickly than they would have without a transplant. She further states that donating organs entails a hidden and questionable choice about allocating scarce resources. It commits millions of dollars from the relatively fixed budgets of insurance companies in an attempt to prolong a handful of lives. These are all ethical dilemmas that should be considered.

Organ donation is a new and complex issue. Many in our society are uncomfortable with the process. It has raised many ethical and moral questions regarding what has happened and the fear of what can happen. With organs being in short supply, there is a possibility for money, influence, race, religion and nationality to creep into the

¹³ Susan E. Morgan, "The Power of Talk: African Americans' Communication with Family Members about Organ Donation and its Impact on the Willingness to Donate Organs," *Journal of Social and Personal Relationships*, vol. 2, (2004)

distribution system, according to Sanjay Nagral, an Indian ethicist. In his article *Ethics and Organ Donation* in the *Indian Journal of Medical Ethics*, he raises two possible ethical dilemmas:

1. Should the organ be transplanted into the sickest patient, since he or she needs it most, although they have the poorest chance of survival?
2. Should patients with diseases brought on by addiction (liver disease from alcoholism) be disqualified for fear that the patient may relapse into addiction?¹⁴

Relevant literature is sparse, and the dynamics of the barriers of organ donation in the African American community are still being explored. Chapter three will give the reader more information about the theological, historical and biblical ideas that this researcher found to be important when discussing this subject.

¹⁴ Sanjay Nagral, "Ethics of Organ Transplantation," *Indian Journal of Medical Ethics* 3, no. 2 (2003): 14

CHAPTER THREE

THEORETICAL FOUNDATION

This chapter will discuss in detail the theories behind this ministry project. Breaking the Barriers of Organ Donation in the African American Community has its roots in biblical, theological and historical scholarship. The researcher will also discuss the purpose of the peer group, which is Pastoral Care and Counseling, and how it ties into the ministry of a chaplain, and in particular the chaplain ministering to families whose loved one is a potential organ donor.

Pastoral Care and the Clinical Setting

Hospital chaplains have a unique role in the lives of patients and families because their relationship is short term. Chaplains meet people in a time of crisis, and are often strangers to the family. Those in crisis are looking for someone to step forward and say, “I am here with you.” They are too traumatized to seek help, but will recognize it when it appears. The chaplain shows up to remind them that God is with them. This project is about breaking the barriers of organ donation in the African American community, but it is clear that in breaking those barriers, ministers have some work to do. When they show up it is not about a potential organ donor, but about a patient and family in crisis.

Providing pastoral care is the reason that they are there. The question arises, what is pastoral care? How does one provide good pastoral care? How does one help a family find meaning in their crisis, how do pastoral caregivers respond pastorally?

William B. Oglesby, Jr. defines pastoral care, in a biblical sense, as that function of the people of God wherein we “bear one another’s burdens, and so fulfilling the law of Christ (Gal. 6:2) as the means for participating in the process of reconciliation.”¹⁵ He also describes it as a process where one sits with patience and compassion, offering a hand when it is evident that one is fearful but also to rejoice with them when the shadow passes over them. Clinical chaplains often do not have the opportunity to rejoice with those who have gone through the painful experience of an unexpected death. The chaplain was with them during the difficult times, and then tries to help them to take the next step in their grief.

This chaplain has observed in recent years the increase in patients asking to see a chaplain. There has been a tremendous shift in the patients’ ideas of what they are looking for when the chaplain arrives. Chaplains are now seen as a part of the healthcare team, so patients and families trust that the chaplain is aware of the medical condition and all of its ramifications. Patients are now looking for a more holistic view of medicine and counseling. There appears to be a deeper hunger for a more fulfilled spiritual life and connection with God when they are faced with a crisis in their lives.

Emmanuel Y. Lartey, in his book *In Living Color*, offers a definition of pastoral care, which this chaplain has found helpful:

¹⁵ William B. Oglesby, Jr., *Biblical Themes for Pastoral Care* (Nashville: Abingdon Press, 1990), 39-40.

Pastoral care consists of helping activities, participated in by people who recognize a transcendent dimension to human life, which, by the use of verbal or non-verbal, direct or indirect, literal or symbolic modes of communication, aim at preventing, relieving or facilitating persons coping with anxieties. Pastoral care seeks to foster people's growth as full human beings together with the development of ecologically and socio-politically holistic communities in which all persons may live humane lives.¹⁶

This definition covers compassion and concern for one's neighbor and being able to show that compassion through activities. These activities can be done through prayer or reading scripture, listening to the stories with an empathetic ear. There are times when being pastoral means giving them a cup of water, passing them a tissue for their tears or making telephone calls. This will often lead to trust, and that will lead to a meaningful discussion about their situation or crisis. Sitting with patients and families during their crisis is a ministry of presence. This writer was with a father whose family had been in a terrible accident; they were on vacation and driving to the beach when a truck hit their car. His three-year-old son was in the trauma bay with massive injuries and the child died a few hours later. The writer received a phone call from the father eight weeks later and was invited to read the eulogy given by him at his son's funeral. He commented in the eulogy how the chaplains helped him and he said, "I don't remember what they said to me, but their presence was calming."

The ministry of presence crosses racial and cultural lines. When ministering to families of potential organ donors, the same holds true: being present, listening, assessing grief and being alert to family dynamics are all a part of good pastoral care to those that are going through a crisis. The parish minister is not always equipped to help their parishioners deal with crisis situations and the inner struggle that they might be

¹⁶ Emmanuel Y. Lartey, *In Living Color* (London: Jessica Kingsley Press, 2003), 30-31.

experiencing from such devastating events as a sudden death, especially if that death is the result of a trauma.

A new paradigm for pastoral care giving has surfaced in the twenty-first century. Traditionally individuals have been viewed as a “living human document,” but now Bonnie Miller-McLemore has introduced the “living human web.” She states that the person-in-relationship relates to connectedness to society, family systems, public policy, institutions and ideologies.¹⁷ She suggests that it is not enough to understand the theological paradigm, but one must also understand the social context through sociology, ethics, culture, and public policy. These factors are very important when ministering to those who are facing end of life decisions. In providing pastoral care one will have to examine not only the physical body, but also the broken soul and spirit. The twenty-first century paradigm includes the whole person, body, mind, and soul. It is important to bring wholeness to the broken and to integrate psychology with religion. It is important that pastoral care givers help patients and families reach within themselves where their faith lies and look for the strength that God has planted in each human being.

Hospital chaplains are trained in the clinical setting. They learn medical terminology and how to interact with the multidisciplinary team which includes doctors, nurses, and social workers. This is important because, in building a relationship with patients and families, a clear understanding of the medical condition is helpful. Many times it appears that patients and families can only hear the chaplain because of the trust that has been established. Clinical Pastoral Education (CPE) is the method from which chaplains learn to integrate the medical with the spiritual. It enhances the gifts that the

¹⁷ Jeanne Stevenson Moessner, *Through the Eyes of Women: Insights for Pastoral Care* (Minneapolis: Fortress Press, 1996), 7.

minister already possesses so that he or she is better able to minister in the clinical setting. CPE is an interfaith learning process for theological students and ministers, with a supervised encounter. It is a process of looking at oneself as well as those to whom one is ministering. Transformation takes place as one theologically reflects on the human condition, specifically either mental or physical illness.

Chaplaincy is a specialized profession, and a parish minister is not always equipped to help their parishioners deal with crisis situations. They are often dealing with the inner struggles from a traumatic experience, and it requires the expertise of one who is clinically trained to handle those situations. It takes education beyond seminary (namely CPE) to competently counsel those persons trying to make decisions in the clinical setting. Without proper training, clergy can sometimes do more harm than good in trying to counsel those dealing with deep grief issues. A pastor should also have the skills to assess the situation and refer parishioners to outside counseling. This writer is not suggesting that a pastor cannot counsel those that are grieving; however, in some situations, a minister with clinical training is better equipped.

Hospital chaplains also work with the tension of ministering to those whose faith might be different from their own. A Christian chaplain many times has to minister to those from the Jewish, Buddhist, Hindu, Muslim, and Atheist communities. CPE instructs students to understand their work in terms of their own denominational experience and faith background. Chaplains are trained to use neutral language in the care of patients. One of the most rewarding experiences that this chaplain encountered was supporting a family whose faith was Hindu; during that time, it became clear to me again that in times of crisis, those hurting only want authentic compassion.

Hospital chaplains are trained to listen to the stories of patients and families. Stories help people find meaning and order in the chaos of their disrupted world. The meaning of a trauma situation can be found in the stories patients and families tell. It is not about the factual information, but rather the history that patients and families reveal. There is a paradigm shift for professional chaplains because hospitals are looking at budgets and bottom lines. Hospital administrators are weighing the cost effectiveness of chaplains. They are looking for definable outcomes that can be validated, when the primary task of chaplains is dealing with matters of the heart and soul, which are often immeasurable. Limited research has shown that patients who are regularly visited by the hospital chaplain have shorter hospital stays and require less pain medication. There is also a decrease in calling the nurse, which saves time and money. These are quantifiable results and the hospital chaplain has to balance their responsibility to hospital administrators with their responsibility to patients.

Biblical Foundation

Beliefs about the body are often formed through one's religious tradition. The practices, biblical texts, and teachings inform how one reacts to stressful times in one's life. Organ donation often raises religious concerns about the relationship of physical and spiritual realms; implications for the afterlife, either during this lifetime or after death. The teaching in many faith traditions is that the body is a gift from God. The Bible does not, of course, mention organ donation and what decision should be made. Twenty-first century technology causes us to constantly wrestle with the ancient text in terms of today's society. It is up to clergy and people of faith to lift major themes throughout

scripture that can be used in the context of moral dilemmas that one is faced with in today's society.

It is clear throughout the Bible that God requires us to be charitable and giving individuals. Giving is an act of charity (1 Cor. 13:3). Margaret Mohrmann in her book, *Medicine as Ministry*, finds that organ donation is not a self-donative love but stewardship. She writes "The call to stewardship is a call to recognize the basic fact of our existence: all that we are, all that we have, all that we can do is ours – is under our authority - by virtue of God's creation." She argues that stewardship entails good use of God's gifts. One of the core biblical teachings about stewardship is the parable of the talents (Matt. 25:14-26), in which three men are given one, two, and five coins to use. The one that hid his talents in order to return it unchanged to the giver is castigated in the strongest terms. Those who invested wisely and doubled the amount of their gift are praised by Jesus.¹⁸ This passage of scripture is about money, but it can be extrapolated to other aspects of our lives, including our bodies. In keeping with the spirit of the parable, organ donation rises with scripture: "I was hungry and you gave me food" can be extended to the health care world, "I was bleeding and you gave me blood" and "my heart is failing and you gave me a strong heart of your loved one who is brain dead." It is important to note that this can also extend to living donors giving a kidney, bone marrow, and corneas. Organ donation is an act of neighborly love for one's brother or sister (Matt. 7:12)

Families struggling with the decision of donating their loved one's organs often say that their family member was a loving and giving person. They will cite examples of

¹⁸ Margaret E. Mohrmann, *Medicine as Ministry* (Cleveland: Pilgrim Press, 1995)

unusual sacrifices that their loved one made for their family and friends. This chaplain has noticed that these families will agree to donate their loved one's organs because they feel that this act is in keeping with the way the patient lived his or her life. If patients have not made their wishes known by their driver's license or donor registry, it is their families who suddenly become the stewards of their loved ones' bodies. Their biblical understanding and foundation is the one that is explored, which leaves families in moral dilemmas, asking themselves, "Is this what I would do or what they would do?"

The bodily resurrection is the issue most often raised, and the one that many families seem to dwell on when considering organ donation. Statements such as, "I'm taking everything back with me," or, "I need my body to exist in eternity," are often heard. Those in the medical community might find these reasons absurd, but it is what some people believe. This chaplain hears these remarks more frequently from the African American community than from any other ethnic group.

The Apostle Paul addresses resurrection of the body in his letter to the Corinthians. 1 Corinthians 15:35-58 is especially important in the discussion of the bodily resurrection. Verse 35 states that someone asked the question, "How are the dead raised and with what kind of body do they come?" This leads Paul into a discussion in which he compares the body to seeds that have been planted. This passage of scripture suggests that what is sown is perishable and what is raised is imperishable. It is sown in dishonor and raised in glory. The earthly body can be destroyed, through trials of life, such as sickness, sin and through the hands of others, but the eternal body will have power and cannot be destroyed. It will be imperishable; in other words, it will never die. In discussing organ donation we are talking about the perishable body, the body that can

CHAPTER FOUR

METHODOLOGY

This chapter will describe the research method for this project. I chose the qualitative research method in the form of case studies. The findings are described in a narrative form. The writer, being a hospital chaplain, was sensitive to the fact that the participants were still grieving and that the subject matter might make them relive their traumatic experience. Qualitative research allows chaplains and other pastoral caregivers to call upon their empathic listening skills. Getting a clear sense of what the participants were feeling was paramount in understanding the motive behind saying yes or no to donation. This researcher tried to report the painful experiences that the families endured. It was also important to capture the joy and healing that they expressed because they decided to give the gift of life. Action research was used because it focuses on solving real problems, and the low donation rate in the African American community is a real problem. The knowledge gained will be used to help increase consent rates for organ donation. Organ donation cases do not happen on a regular or consistent basis; therefore most of the information will come from past experiences. Interviews were initiated with family members of organ donors.

This researcher chose to interview three families. These families were chosen because of specific circumstances, such as family dynamics and sociological background. The first family was chosen because organ donation was something that the decision

maker (mother) would not have chosen for herself. The second case was chosen due to the role of the pastor and his influence on the decision maker. The third case was chosen because there was no identifiable faith background. The interviews were casual and in a relaxed setting. This writer sought to redevelop trust to enable the families to be honest with their responses. The writer wanted the interviewees to share a very personal moment in their lives. The tone was conversational, because of the sensitivity that the writer felt for the families. The families interviewed were families that this writer worked with at the time of their loved ones' deaths. The writer remembered the pain and grief that they felt at the time of death of their loved one. The writer admits to the bias of protection for these families. She was looking for answers to the following questions.

1. Was there ever a conversation between you and the donor about organ donation?
2. Had you ever thought about organ donation?
3. Are you a member of a church? Was the donor a member of a church?
4. How were you treated in the Intensive Care Unit?
5. Did you completely understand the concept of brain death?
6. Did you feel supported by the chaplain?
7. If you are a member of a church, did your pastor come to the hospital?
8. What role did he or she play in your decision?
9. How did family dynamics inform your decision?
10. Are you an organ donor?
11. What was the main reason that you decided to make your loved one an organ donor?
12. Did you feel that the timing was right for the request?

13. What are your thoughts about African Americans and organ donation?
14. Did you ever think about the race of the recipients?

Purpose of Study

The purpose of this study was to examine the barriers to saying yes to organ donation for African Americans. Once the barriers were identified, the writer looked for ways to break those barriers. She was looking for the role that the church or the hospital chaplain played in helping the family to make a decision. She was also trying to determine the effectiveness of having the hospital chaplain bring up the subject of organ donation prior to the introduction of the transplant coordinator from the Organ Procurement Organization.

CHAPTER FIVE

FIELD EXPERIENCE

This chapter will report the findings of the interviews with three families. Each case will be presented in narrative form, to give the reader a sense of the grief that the families are still feeling. It is important to the writer that the reader understands that this study is not looking for a simple “yes or no” answer. There are feelings, beliefs, and cultural nuances that lead people to make a life altering decision about organ donation. Both the families of the donors and the organ recipients’ lives are changed forever.

Case 1

The potential organ donor was a forty-six year old African American female who suffered a stroke. The patient was married, but estranged from her husband. The husband visited the patient on many occasions, but deferred all medical decision making to the patient’s mother. The patient has a living mother, stepfather and one sibling, a brother. The patient arrived at the hospital breathing unassisted, but her condition deteriorated within the next ten days. When the patient met the clinical trigger with a Glasgow Coma Scale of less than four, LifeNet was called with the referral that the patient was a possible organ donor.

During the ten days that the patient was in the Neuro-Intensive Care Unit, the chaplain supported the family by listening to stories, praying and providing grief counseling. The family held on to the hope that the patient would get better. The family was devastated when the patient's condition worsened. When the patient started progressing towards brain death, the chaplain spent significant time with the family, especially the patient's mother. The patient did progress to brain death, and this chaplain was with the family when this news was shared. Since the patient was declared brain dead, she then had the unique opportunity to become an organ donor.

The chaplain recognized the intense grief of the mother and decided to talk with the patient's stepfather about how to approach his wife about organ donation. The stepfather made the statement that when he renewed his driver's license; he registered to be an organ donor. He stated that when he made his wife aware of that, she was against it and said she would never become an organ donor. This information left the chaplain assuming that the patient's mother would say no to organ donation. The brother had not yet arrived at the hospital, so the writer decided that she would wait for the brother before approaching the mother. In the meantime, the chaplain did approach the husband, who thought it was a good idea, but made it clear that the decision was up to his mother-in-law. When the patient's brother arrived, he spent time in the patient's room and then the chaplain spoke with him about organ donation. When they started to talk, his mother approached and wanted to know what the conversation was about. The chaplain then talked with the mother, with the stepfather and brother present. She explained that her daughter had the unique opportunity to become an organ donor due to her brain injury. The mother's first reaction was to look at her husband and son to see what they thought.

They both told her that they were organ donors and that they thought it was a good idea. She stated if they thought it was a good idea she was for it, but she wanted her son-in-law's opinion. The chaplain explained that she had spoken with her son-in-law and he was open to the idea but felt that she should make the decision. Therefore, the mother consented to organ donation.

A transplant coordinator from the Organ Procurement Organization was called in to explain the process formally, and to have the family sign the consent forms. This chaplain returned to the patient's room with the family for prayer; by this time there were several family members present. After she prayed, each family member kissed the patient goodbye and left the room. The mother was the last to leave the room. After spending time alone with her daughter, the mother exited the room, and stated that she had changed her mind, and did not want her daughter to be an organ donor. She said she wanted her daughter to stay the way she was and did not want her to be cut. This chaplain said to her, "No you don't, your daughter has a glorified body now. You do not want your daughter to remain with all of the health problems that her body has. She has a new body." The mother smiled and said, "You are right." She went back into the room, kissed her daughter, and told her to enjoy her new body.

Case Analysis

I interviewed the mother about her experience and feelings surrounding the process of organ donation and her daughter. The interview was conversational and was about one hour in length. The first twenty minutes was spent helping the mother process her grief. She stated how much she missed her daughter, because prior to her stroke, they

did most things together. She stated that she has not been to Wal-Mart since her daughter's death because it was too painful, as that was their favorite place to go.

The mother stated that her church and pastor had been helpful during this tragic time, but that, as time went on, people stopped being attentive. Her daughter did not attend church on a regular basis, even though she was raised in that particular church. The researcher directed the conversation toward the impact of her daughter's organ donation. The mother stated that she has thought about it a lot. She wonders about the people that her daughter had helped (both kidneys were recovered), and if they are still on dialysis, and how they are doing physically. She stated that it was helpful when she received the letter from the Organ Procurement Organization giving her some information about the recipients. She stated that she had never wanted to be an organ donor and that she was not ready to sign up, but that she was considering it. She was struck that her son and husband were both organ donors, because she knew about her husband but did not know about her son. That information, according to her, played a large part in her saying yes to donation. The conversation then moved to the process. This researcher asked her about the mother's treatment at the hospital. She stated that she was pleased that everyone was compassionate and caring. She did not worry about the care her daughter received when she wasn't present, because she trusted the staff. She was thankful that everyone was patient with her as she tried to understand and come to grips with the grave prognosis. She was thankful for the chaplain's presence because she explained things in layman's terms. She was thankful for the spiritual care she received from all of the chaplains that visited her and her daughter. She stated that when this chaplain first mentioned organ donation, she was a little stunned because she had never thought about it. She felt the

timing was good, and she was glad that it came from the chaplain because she had come to know her over the few days that they had been together. She never heard her daughter say that she wanted to be an organ donor, but she stated that she was so much like her brother that if he thought it was a good idea, she is sure that her daughter would have felt the same. The researcher asked her if she ever thought about the race of the recipients, and she said that when she pictures them in her mind, she thinks of them as black, but if they are not, it's okay.

I asked her why she thought that, for the most part, African Americans do not consent to donation. She said it is not something that is talked about. She said that when her husband told her he signed up at the Department of Motor Vehicles, she was a little upset wondering why he would do such a thing, and did not want to think about it or discuss it. She stated that she put it in the same category as an autopsy or cremation, and that they are both distasteful. She said that preserving the body means everything, and to think that someone was cutting up a body just did not feel right. She also talked about memories as a child when they would bring the bodies of relatives or friends back to the house for the "sitting up," and someone would sit with the body all night, to protect it. Degrading the body is the worst thing one can do in the black community, according to the interviewee. This researcher asked her how she felt about that now. She stated that when the chaplain mentioned a new body, it made sense to her that we do not go to heaven with these broken down bodies.

Summary of Case 1

This case was chosen because of its theological implications and family dynamics. The discussion of what happens to the physical body after death was very

telling. It was also interesting because the husband deferred to his mother-in-law, and the brother and stepfather were both registered organ donors. Therefore, the mother was influenced by three things: 1) Her family was pro-donation; 2) She trusted the chaplain; and 3) She was able to make sense of the resurrection of the body. The mother was surrounded by those who made her feel comfortable and safe. This researcher spent a lot of time talking to the family about organ donation. It was important that the news did not come unexpectedly from a stranger. This case started with the chaplain finding out through family members that the mother was not an advocate of organ donation. With time to build trust, the chaplain was able to break down the barriers by making sure that there was clear communication between the family and the medical staff. She also used her pastoral skills to talk with the mother about the resurrection of the body. These two important components led to a positive outcome. Building trust and relationships with families is the key for a positive outcome.

Case 2

The patient was a twenty-two year old African American male who was shot in the head during an altercation with another African American. The patient had a mother and no siblings, and his father was not a part of his life. The patient was close to brain death when he arrived in the emergency room, and he quickly progressed to brain death. He was moved to the intensive care unit, where he was declared brain dead by two physicians, including a neurosurgeon. The mother's pastor arrived, and this chaplain knew the pastor from a workshop that she facilitated for community clergy about advance directives and end of life issues. During that workshop, there was a discussion about organ donation and the process. It was clear that the mother had a meaningful

relationship with her pastor. The pastor was helpful because the mother was overcome with grief. When the mother was told that her son was brain dead, she climbed into the bed with him. The pastor spent time alone with her and asked this chaplain for suggestions on how to help her. The chaplain suggested giving her more time alone with her son. She told the pastor that the patient had the opportunity to be an organ donor. The pastor agreed to be with the mother when it was time to talk to her about organ donation. This chaplain went into the room and got on her knees and talked to the mother about the opportunity of organ donation. She looked at her pastor and asked him what he thought. He replied, "I think it would be wonderful."

She said, "Okay, I think it would be good, too." The chaplain then told her that a gentleman would be in to talk with her and explain the process, and the mother said, "Chaplain, can't you just tell him I'll do it, because I don't want to talk to him." The chaplain assured her that the coordinator would be kind and gentle to her, and she agreed to meet with him.

Case Analysis

This researcher interviewed the patient's mother approximately one year after her son's death. The interview was in a conversational style, and ran for approximately one hour. It was obvious that the mother was still feeling intense grief. She spoke of losing her only child, and the fact that she would never have grandchildren. She talked about how hard it was to go about her daily activities. She spoke of her anger, and stated that if she wasn't a strong believer in God, she might seek revenge. The chaplain made a mental note to suggest a support group.

This researcher asked her if she was still involved in her church. She replied that it was the one thing she looked forward too. She spoke about how supportive the church and pastor have been. I began to ask her about her experience at the hospital. She stated that she could not have asked for better care. She talked about the nurse who cut a lock of her son's hair, and how she saw nurses with tears in their eyes. She said they seemed to feel her pain. She felt that the doctors did a good job of explaining what happened to her son's brain, and that, even though it was hard to hear, she understood it. When this chaplain mentioned organ donation, right away she felt it was what her son would have wanted, but if her pastor had not seemed positive, she may not have agreed to the procedure. She has a lot of confidence in her pastor and his opinion, so she was glad he agreed with organ donation. It brings her comfort knowing that someone lived because of her son's heart. She often thinks about that person and her hope is to meet him or her one day. This researcher asked her if it mattered to her the race of the recipient, and she said not at all. She stated that everyone is one of God's children. She said she never gave it much thought that African Americans generally are not organ donors. She could not understand why you would not want to help someone have a better quality of life or even live longer.

Summary of Case 2

This case was chosen because of the role of the pastor. It is clear that even though the mother saw organ donation as a positive thing, she would not have agreed to organ donation if the pastor did not agree with her. The pastor participated in a workshop sponsored by the Lions Eye Bank with five other pastors. This writer facilitated that workshop, which included topics such as advance directives and end of life decisions.

The advance directive form includes a section on organ donation, which sparked a lively discussion with these pastors. The pastors stated that a lot of their questions were answered, and that they would not have asked those questions in another setting. They stated that because the workshop was in a clinical setting facilitated by a clinical chaplain, they felt comfortable asking their questions.

The writer was surprised that the pastor in this particular case was one of the pastors from the workshop. This made a huge difference in the positive outcome of this case. If her pastor had been present and had not been an advocate of organ donation, this writer believes that the mother would have said no to donation.

Case 3

The patient was a fifty-two year old African American woman who suffered from a stroke. The patient progressed to brain death two days after admission to the hospital. The patient was single with two adult daughters. The patient and her daughters were not members of a church, but they did accept prayer when it was offered. They appeared to be mistrustful of the medical staff and were rude, at times using profanity. They accepted the chaplain's presence, but did not interact with her. When the doctors told them that their mother was brain dead, they began to wail and one daughter passed out on the floor. This chaplain waited and was present with them as they grieved the loss of their mother. When they calmed down, this chaplain, at the appropriate time, told them that their mother had an opportunity to be an organ donor. They said no immediately. When this chaplain asked if they thought their mother would want to be an organ donor, both daughters replied that she would not want that. They did not consent to organ donation.

Case Analysis

This researcher found it difficult finding families who did not consent to organ donation to interview. One of the daughters of this patient agreed. The conversation started with the chaplain asking what kind of support they were receiving for their grief. The daughter stated that the family was there for one another. She stated that she felt the hospital staff did their job, but she never said anything positive beyond that. She stated that she and her sister understood what was going on, and they understood brain death. She also stated that the chaplain was helpful in getting information for them. She stated that they did not believe in organ donation, since she did not want her mother's body to be cut and she did not think her mother would want that. This researcher tried to explore the reasons why she did not believe in organ donation. She stated, "I would not give and I would not take an organ....when it's your time, it's your time."

Summary

This family was chosen because of the lack of communication. It was apparent that they did not trust the medical system. It was hard to communicate with this family, since they did not talk much and did not have a faith background. They appeared to be from a lower economic status. They also did not appear to have an education beyond high school, and it is questionable whether they were high school graduates. This is the community that is most difficult to reach and educate about organ donation. Workshops

do not happen in these communities. Health care is not a priority; therefore organ donation is not seen as a priority. This is a clear example of families who are not in places where organ donation is discussed, hence resulting in a negative outcome in regards to organ donation. This writer tried to explore with them their beliefs behind their negative reaction to organ donation without any results.

Reflections

This project has been a work of passion for this researcher. This project has been a project of healing, and an opportunity to find meaning in the death of a cherished family member. The research and answers found are already being utilized in the context of the researcher's role as chaplain. The project has already made a difference. When providing pastoral care to those who are in crisis, especially African Americans, this writer will be looking for threads of commonality tying into this project. This writer was humbled by the interviewees, and grateful to the families who were still grieving, but took the time to talk and share their experiences.

This project started with the question, how can the barriers of organ donation be broken in the African American Community? This writer is an African American and knows of the mistrust of the medical system. She also knows that the African American Church is silent on the subject of organ donation. She has heard in the community that organ donation is basically mutilation, and that it is important to go to heaven with all the body parts that God has given us. This researcher is beginning to see a shift in the mindset of African Americans. African Americans are becoming organ recipients, and an increase in the consent rate is taking place. Being a chaplain in a level one trauma center puts this researcher in the position to talk to families about organ donation. She has

ministered to families going through the crisis of having loved ones injured, dying, and becoming potential organ donors. When she first started working with families of potential organ donors, she was told that she could not mention organ donation. The belief was that a chaplain should support them pastorally and make sure that there is clear communication between doctors and families, and that alone would make a difference in the consent rates. She found that it did not make a difference to just support; rather, one must be proactive about organ donation. To be proactive, one has to understand the culture of African Americans, family dynamics, biblical beliefs, theological beliefs, and the historical reference. Providing pastoral care in the African American community means that one must understand that one is providing pastoral care to many who have felt the sting of racism and oppression. It is also important to note that when providing pastoral care in the clinical setting, one has to consider all members of the family, because African Americans do not make decisions in isolation. When speaking with families about organ donation, it is important to include the whole family and not just the legal decision maker.

This writer found that one of the major barriers to organ donation in the African American community is religious beliefs. It is documented that all faiths and denominations except the gypsies believe in organ donation. However, people have their personal beliefs, which many times are in conflict with their denominational beliefs. The one belief that this researcher hears most often is that it is important to keep the body intact. Some believe that one has to go to heaven with the body intact, and some believe that when the resurrection comes, one's body has to be intact. This writer began to explore with families Paul's letter to the Corinthians about the resurrection of the dead:

“Your body is sown a physical body, it is raised a spiritual body” (1 Corinthians 15:44).

As the reader will recall, in one of the cases that was researched, the mother lit up when the chaplain said that her daughter now has a glorified body, breaking the barrier against organ donation.

In the experience of the writer, the scriptural reference to love thy neighbor or the parable of the talents does not really make a difference. People already understand that to be a Christian you are commanded to love your neighbor, which includes charity. People do not equate giving organs to loving thy neighbor; hence this was not found to be a barrier. You do not have to be a person of faith to want to help someone. It is a Christian, however, who is concerned about the body remaining intact for the resurrection. Historically, African Americans have a mistrust of the medical system. Lack of access to health care, unethical studies such as the Tuskegee Study, memories of segregation in hospitals and doctor's offices, and, of course, slavery all leave African Americans wondering if medical professionals are telling them the truth. In the experience of this writer, many times families will not come to family conferences with doctors because they do not want to talk about end of life issues. African Americans often feel that hospice and palliative care means abandonment and lack of treatment. When offering the option of organ donation, these facts should not be ignored. One family member told this writer that the Organ Procurement program wanted his son's organs for a Caucasian person. Some people fear that if they sign up for organ donation through the Department of Motor Vehicles or the Donor Registry, they will not be given every opportunity to survive. Establishing trust in the medical system with the African American community will help break these barriers.

While working on this project, this writer's role as chaplain began to change regarding the way families are approached concerning organ donation. When the organ donation protocol was set up, it was clear that only the OPO would approach families. The chaplain was to support the family throughout the process, but not mention organ donation. The chaplain was listening for an understanding of brain death and to help families process their grief. Once the patient was declared brain dead, the chaplain would then introduce the transplant coordinator from the OPO. Most of the time, the OPO would receive a negative response regarding organ donation. The chaplains, in consultation with the OPO, decided to mention organ donation to the family as a way of preparing the families to talk with the OPO. The chaplain would often talk to family members who seemed to be in charge about how to approach the rest of the family. When the chaplains started this new format, they started consistently getting an answer of yes to donation. This led to a new model and an increase in organ donation rates, including within the African American Community. This project was instrumental in providing data to support this new model.

I believe that having the chaplain make a preliminary mention of organ donation makes a difference. Families see the chaplain as a minister or pastor, and that automatically in most cases sets up trust. If their minister is present and puts his or her stamp of approval on organ donation, families tend to say yes to organ donation. The presence of the chaplain has the same effect, maybe even more so, due to their clinical training. Their pastoral skills allow them to observe families from a different viewpoint than that of the OPO or other medical professionals. They can sense mistrust or lack of understanding and either help to explain or get someone who can. The chaplain is a

member of the multi-disciplinary health team, so the clinical team also trusts that the chaplain will interact appropriately with the family.

Summary

This researcher hopes that the following recommendations will be helpful to other hospital chaplains and parish ministers when ministering to families of potential organ donors.

1. Connect with the family as soon as possible after their arrival at the hospital, especially if their loved one meets the clinical triggers (GCS<4) for organ donation.
2. Identify the leader or dominant member of the family; this might be an older relative or it can be a friend of the family. It is the person whom everyone seems to be turning to and the one who is most calm.
3. Become the liaison between the medical staff and the family.
4. Make sure physical comforts are taken care of, such as water, tissues, and a quiet room where the family can have privacy.
5. Listen to their stories about the patient.
6. Pray with them and read scripture.
7. Give them privacy; they might need to talk about private matters with other family members.
8. Be the gatekeeper if they tell you they do not want visitors.
9. Be present when doctors talk to them, especially when giving them the news that their loved one is brain dead.
10. Do not be afraid to let your emotions show; it is all right to share tears.

11. When you feel that the family is ready to hear it, prepare them for the visit of the Organ Procurement Organization. Example: "I know you have heard devastating news, and I want to prepare you for what will happen next. Because of your loved one's brain injury, he or she has an opportunity to be an organ donor. When you are ready, I will get the representative from the Organ Procurement Organization for you." Many times this leads to a conversation among family members, and it is important that you stay present in case they have questions or you hear inaccurate information such as, "if we do this, then we can't have an open casket." If they ask what you think, it's okay to say that you think it is a good idea. You can tell them that a lot of families find meaning and healing in donation.
12. Introduce the transplant coordinator.
13. Stay and support the family until they leave the hospital; support them regardless of whether they say yes or no to donation.

Community Clergy

Many times community clergy do not understand the protocol of organ donation. It was helpful that this writer had the opportunity to gather a few clergy (6) and discuss end of life issues. The agenda was to cover advance directives and organ donation. The Lions Eye Bank sponsored the workshop, and lunch was provided. The clergy members who were invited were African American. They all admitted that they were not informed about end of life issues as they relate to the hospital. They also found it helpful to go over the advance directive form in detail. They asked more questions about organ donation than about any other part of the form. This was a clear indication of how much education

is required with African American clergy. Educating community clergy has more of an affect on the organ donor registry through the Department of Motor Vehicles. If people hear it discussed by their pastor, they are more likely to become organ donors when they renew their driver's license.

Summary

There is a major need for outreach in the African American community concerning organ donation. There are many people with kidney disease who are on dialysis, or who are suffering from liver disease or heart disease. Unfortunately because of the high lack of health insurance in the African American community, there are many health problems that go undiagnosed until it is too late. African Americans in the medical field have to be educators in the community so that they can eradicate mistrust. The church is the main African American institution of education. That important resource should be used to open the minds of its parishioners about health care. The church has a responsibility to its members to lift the veil of oppression and empower its members to take control of their health care. There is hope that the community will care for their neighbor. This writer has found an increase in organ donation rates in the African American Community.

When this writer started this project, the concern was community clergy; however, as the writer began to do the research while also working in the context of Sentara Norfolk General Hospital, this writer began to see that it is the chaplain who really makes the difference in the hospital setting. The presence of the community clergy is a plus, but not always necessary for a family to consent to organ donation.

At first, it was frustrating because there is not a lot of literature on this topic; but that brought about the realization that this research project is important because there is nothing else written on this topic from a minister's point of view. Every day, someone dies waiting for a heart, kidney, liver, lungs, or pancreas. People are sitting in dialysis centers for hours hooked up to dialysis machines. Ministers can make a difference in saving some people's lives and providing a better quality of life for others. Health fairs are held in most churches, but they rarely address organ donation. The African American church is the core of the community, and if their clergy take the lead on educating themselves and then educating their congregations, both those on the organ donation list and those who have lost loved ones will be positively impacted.

Organ Donation Procurement agencies need to go directly to pastors, rather than waiting for the pastors to come to them. Inviting clergy to the table will lead to discussion about this important topic, and this writer suggests an open dialogue. It would be helpful if African American clergy who are advocates of organ donation would put organ donation on the agenda of their ministerial alliance meetings.

The majority community is donating at a much higher rate than the African American community. African Americans have more to gain from an increase in organ donors, because this is the community that is in need of kidney donors in particular. Poor health care, poor nutrition and poor education lead to more people dying and/or a poor quality of life. It is imperative that something be done, and it has to start in the church, because many African Americans believe that we are our brother's keeper.

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